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Discrimination and genetic privacy

Argentina: draft resolution

Genetic privacy and non-discrimination

The Economic and Social Council,

Guided by the purposes and principles set forth in the Charter of the United Nations, and also by the Universal Declaration of Human Rights,[1] the International Covenants on Human Rights[2] and the other relevant international human rights instruments,

Referring to the Universal Declaration on the Human Genome and Human Rights adopted on 11 November 1997 by the General Conference of the United Nations Educational, Scientific and Cultural Organization[3] and to General Assembly resolution 53/152 of 9 December 1998 endorsing the Declaration,

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[1] Resolution 217 A (III).

[2] Resolution 2200 A (XXI), annex.

[3] United Nations Educational, Scientific and Cultural Organization, Records of the General Conference, Twenty-ninth Session, vol. I, Resolutions, resolution 16.

Recalling Commission on Human Rights resolution 2001/71 of 25 April 2001 on the question of human rights and bioethics,[4]

Recalling also the decision taken on 7 May 1998 whereby the Executive Board of the United Nations Educational, Scientific and Cultural Organization established the International Bioethics Committee, which is carrying out work on confidentiality and genetic data,

Recalling further that the life and health of individuals are inevitably related to developments in life sciences and social areas,

Acknowledging the importance of advances in genetic research, which has led to the identification of strategies for early detection, prevention and treatment of diseases,

Bearing in mind that humanity should participate in the evaluation of the implications of the genetic revolution and guide its applications in an open, ethical and participatory manner,

Reaffirming that the information obtained from genetic tests, which is personal, should be held confidential based on the conditions set by law,

Recognizing that genetic data associated with an identifiable person can in some instances be specific to other members of the individual's family or community, and that the rights and interests of such persons must also be taken into account in the handling of such data,

Stressing the fact that revealing genetic information belonging to individuals without their consent may cause harm and discrimination against them in such areas as employment, education, social and medical insurance,

Recalling that in order to protect human rights and fundamental freedoms the limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights,

1. *Urges* States to ensure that no one shall be subjected to discrimination based on genetic characteristics;

2. *Also urges* States to protect the privacy of those subject to genetic testing and to ensure that genetic testing is done with the prior, free, informed and express consent of the individual or authorization obtained in the manner prescribed by law and in accordance with public international law and the international law of human rights;

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[4] See Official Records of the Economic and Social Council, 2001, Supplement No. 3 (E/2001/23).

3. *Invites* States to take appropriate specific measures, including through legislation, to prevent the use of genetic information and testing leading to discrimination or exclusion against individuals or members of their families or communities, in all areas, particularly in social, medical or employment-related areas, whether in the public or the private sector;

4. *Calls upon* States to promote, as appropriate, the development and implementation of standards providing greater protection with regard to the collection, storage, disclosure and use of genetic information taken from genetic tests that might lead to discrimination or invasion of privacy;

5. *Urges* States to continue to support research in the area of human genetics and biotechnology, subject to accepted scientific and ethical standards and to the potential benefit of all, especially the poor, emphasizing that such research and its applications should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics;

6. *Requests* the Secretary-General to bring the present resolution to the attention of all Governments and relevant international organizations and functional commissions in order to collect the information and comments received pursuant to it, and to submit a report thereon to the Council at its substantive session of 2003.

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